

t^sa

tuberous sclerosis
association

Impact Report 2019



To provide
help for today
and a cure for
tomorrow



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Images of Sir David Suchet CBE courtesy of Mike Dodson

How the TSA helps to improve lives

Paul Maywood (TSC community member)



“My late mother joined the TSA in 1977. I joined in 1995 when I attended an Outlook event in Bristol in April of that year. From 1995 and to the present day I have benefited from this social interaction, including from the virtual events in 2020. Outside of the TSA, I have made friends with TSC community members I met at TSA events, including visiting a number of places both in the UK and abroad with them.”

Philippa Ward (parent in the TSC community)



“The TSA works really hard to offer all kinds of support, information and advocacy to the entire TSC community; be it those who have just received this devastating diagnosis, families trying to navigate the health and care systems, or individuals living with the condition on a daily basis. Thanks to the TSA, I feel strongly connected to other parents of children who live with TSC, giving my family the opportunity to link up with likeminded people who are travelling the same road as us. I also feel empowered that we, in turn, can offer our support to the TSA through jointly campaigning with them for the rights of people affected by TSC. I am hugely thankful and grateful for the work of the TSA and the very special people who are part of this journey.”

Dr Stacey Bissell (Research Fellow, University of Birmingham)



“The TSA has a longstanding position as a global leader in TSC research, with many major TSC research breakthroughs taking place at least in part thanks to the TSA. Through their ambitious research strategy, the TSA continues to play an integral part in TSC research discoveries, to help us uncover further ways to improve lives and ultimately find a cure. Not only that, but the TSA's commitment to patient and public involvement also means that the TSA ensures that the research it helps to fund gives the greatest benefit possible to the TSC community.”

Dr Sam Amin (Consultant Paediatric Neurologist, University Hospitals Bristol)



“For half a century the TSA has been at the forefront of health advocacy and scientific research pushing to improve the diagnosis, treatment and management of people living with TSC. By working on day-to-day policy whilst also funding important research, the TSA help us all to not only better understand TSC but to also ensure that the TSC community get access to new breakthroughs and technologies.

Recently, the TSA’s role in helping to shape the first ever UK clinical guidelines for TSC cannot be overstated, with the charity acting as an important patient barometer and central hub for professionals involved in the guideline’s inception. Thanks to the UK clinical guidelines for TSC, clinicians can be more confident that people living with TSC will receive a more consistent standard of care regardless of where they live in the UK or the number of TSC specialists in their area. Not only that, but the TSA’s own summary of the UK clinical guidelines (including the ‘Easy read’ version of the document) further ensure that individuals and families affected by TSC have access to and understand what level of care they can and should expect from professionals.”

Dr Charlotte Tye (Research Fellow, Kings College London)



“It is critical that charities like the TSA, in which the patient voice is at the heart, are involved in the research funding process. The TSA has long been the driving force behind many of the scientific advances in TSC research in the UK and more widely. The TSA succeeds in bringing together researchers and clinicians as well as the community, each with unique yet complementary skillsets and expertise. I strongly believe that working across disciplines in this way is the key to fully understanding TSC, and importantly learning how to improve quality of life for people living with TSC and their families.”

HOW WE'VE BEEN WORKING TOWARDS OUR NEW FIVE-YEAR STRATEGY FOR 2019 – 2023

We're committed to keeping you updated on our work to hit important targets in our five-year strategy. These targets include all work at the TSA, broadly organised across: The number of people that we reach, our desire to drive TSC research, our incredible fundraisers and our support services.

By having these targets, we can keep focused and ensure that the TSA is doing everything that it can to continue to improve lives affected by TSC.

Increasing reach

Keeping in contact with more people

By the end of our five-year strategy (2019 – 2023), we want to **increase the number of people we're regularly in contact with to 15,000**.

By the end of 2019, we were in regular contact with **4,720** people interested in TSC.

In 2019, we increased the number of people that we're regularly in contact with by **15% (793 individuals)**, including:

- **Individuals with TSC**
- **Wider family members**
- **Parents of TSC Individual**
- **Registered carers of Individual with TSC**
- **Children of TSC Individual**
- **Friends of TSC Individuals**
- **Siblings of TSC Individual**

Plus, we added **75 more TSC professionals** to our contacts in 2019, with the total number in our contacts rising to **154**.

DIGITAL FIRST

The TSA is going through a 'digital first' makeover, where we will focus most of our communications through our website, social media and community emails. This will mean that our work can have the most impact whilst also making it quicker and easier for us to keep you up-to-date on our work.

But, we know that many in the TSC community prefer traditional methods of communication. If you would rather hear about our work by things like post, don't worry, as this will continue.

Social Media

We had a total of **5,047** social media followers by the end of 2019:

Facebook: 3,586

(17% increase compared to 2018)

Twitter: 1,461

Our content was engaged with (likes, shares etc.) **33,088** times and our social media page views were **760,088** – over three-quarters of a million times!

Our **e-newsletters** were read **6,890** times.

Our **website** was visited by **23,889 unique users**. That's equivalent to **one new visitor finding out about TSC and the TSA every 30 minutes throughout 2019!**



Media coverage

Our hard work in advocacy and campaigning, as well as the wonderful work of internationally-known actor Sir David Suchet CBE, allowed us to achieve some fantastic media coverage in 2019:

- Specialist and sector publications: **8**
- Local/regional (including TV): **10**
- National (including TV): **7**



Scan readers

We worked hard to continue to share what the TSA has been up to through our much-loved community magazine, Scan. We also gave Scan a new look and feel to make it easier to read and more accessible – especially for those who read it on phones, tablets and laptops!

Scan was sent to **1,986 households**, with others reading it digitally.

Would you be happy to stop receiving Scan by post and to read it digitally? Let us know (comms@tuberous-sclerosis.org) and help us to reduce overall shipping and printing costs!



TSA community events

Although 2020 has seen us embrace the potential of virtual events, in 2019 we hosted a wide range of face-to-face community events throughout the UK:

Big Day (Nottingham Belfry Hotel)

- 105 attendees and 43 families represented
- 94% rated Big Day "Good" or "Very Good"

Outlook (Mercure Bristol Holland House Hotel)

- 31 registered to attend
- 100% rated Outlook "Good" or "Very Good"

Scottish Get Together (Queen Elizabeth University Hospital, Glasgow)

- 23 attendees
- 75% rated the Scottish Get Together "Good" or "Very Good"

Welsh Info Day (University Hospital of Wales, Cardiff)

- 24 registered to attend
- 81% rated the Welsh Info Day "Good" or "Very Good"

Family Fun Day (Chester Zoo)

- 55 attendees

Northern Ireland Study Day (Belfast City Hospital)

- 16 attendees
- 100% rated the Northern Ireland Study Day "Good" or "Very good"

“ I appreciate how much work goes into organising the event. Thank you for all your hard work ”



“ Everyone was so lovely and supportive. As it was my first event I'd love to come back to a TSA event again. Was lovely to get to know people of different abilities and make new friends who have TSC ”



“ The speakers were very interesting and informative ”

“ Wonderful, informative day ”

“ Great to have opportunity to ask questions to the doctors at the end ”



Driving more research

Between 2019 – 2023 we are aiming to invest or directly stimulate £1.775m into TSC-focused research, meaning the TSA will continue to be at the forefront of TSC breakthroughs with the ultimate aim of finding a cure for TSC.

TSA-funded grant awards

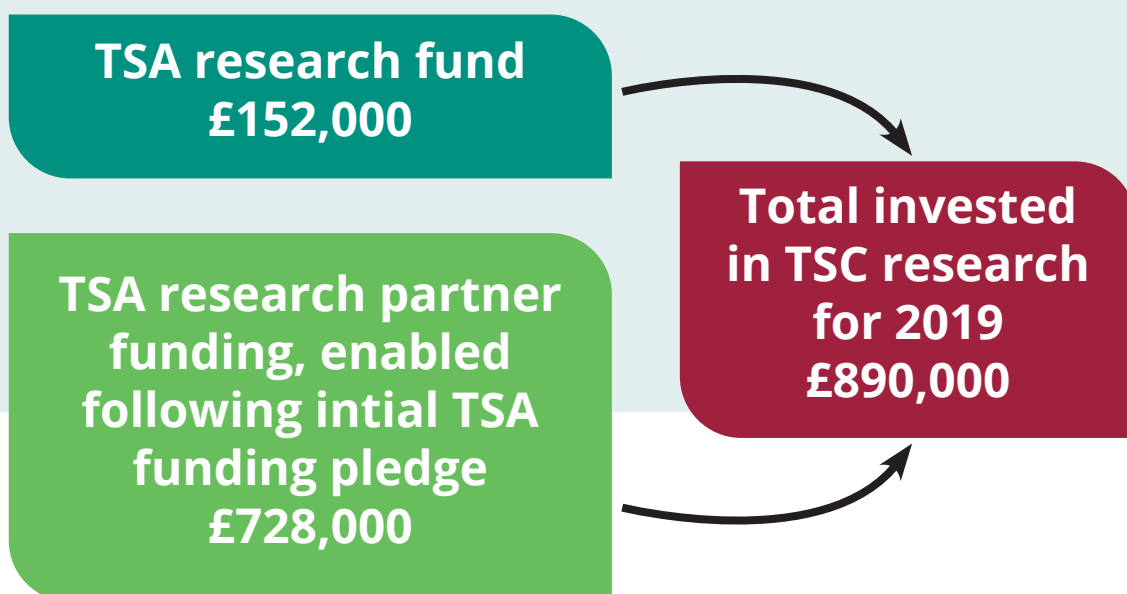
In 2019, of the nine TSA-funded grant awards that submitted data, four of these awards reported six publications in four different academic journals. Five awards also reported 13 other forms of engagement, such as oral and poster presentations at academic conferences or professional meetings.

The benefits of co-funding

In 2019, we started to focus on co-funding as a useful way for the TSA to continue to push forward TSC research whilst getting other parties involved. The benefits of the TSA's new research strategy can be seen in pledged research funds for 2019.

In 2019, we pledged **£152,000** into three separate joint research projects. As a result of the TSA's commitment to co-funding, this initial **£152,000** sparked a further investment into the same three research projects of **£728,000** from other groups.

This means the TSA's **£152,000** research fund for 2019 led to **£890,000** being invested in research overall for the year.



Co-funded research project investments

We invested in three new research projects in 2019 by working with external partners who share our goals:

1. **A model of cell invasion in TSC-LAM**, co-funded with the US Department of Defence - Dr Elaine Dunlop, Cardiff University
2. **The TANDem project**, co-funded with the King Baudouin Foundation - Professor Petrus de Vries, University of Cape Town and Professor Anna Janssen, University of Brussels
3. **Better understanding the accessibility of mental health services for children and young people with TSC**, co-funded with an anonymous major donor - Dr Sam Amin and Dr Ingram Wright, University Hospitals Bristol

We also agreed to fund the Early Development in Tuberous Sclerosis (EDITS) study being carried out by the Institute of Psychiatry, Psychology and Neuroscience with a commitment of **£16,740**, taking our full portfolio in 2019 to **12 live grants** (three of which are joint funded).

Our funded portfolio of ongoing projects
is currently worth **£1,227,575**

Support and information for professionals

A key area of our work in TSC research, treatment and management is giving TSC professionals the opportunity to connect, so that they can learn from each other and share best practice. The TSA Clinics Day 2019, where NHS TSC clinic leaders from throughout the UK came together, had:

- **8** clinics in attendance
- **21** professionals in attendance
- An event satisfaction level of **'Very good' or 'Excellent' for 99% of attendees**

The TSA also worked with the experts who developed the new UK clinical guidelines on TSC, producing a summary version of the guidelines which was shared with NHS TSC clinics and clinicians across the UK, and to patients and carers in the Spring issue of Scan and our website.

Understanding and measuring the impact of TSC research

In 2019, we started using **Researchfish**, an online research reporting tool that enables the TSA to better capture and track the impact of the research we fund.

Major funders that use Researchfish to gather research outcome information include the UK Research Councils, National Institute for Health Research, and over 100 medical charities.

Fundraising in 2019

The TSA would not exist without the incredible individuals, groups and businesses that organise or take part in fundraising opportunities for us. 2019 was no different, with the TSC community rolling up their sleeves in a variety of ways!



LONDON MARATHON

6 runners were there for the TSA, raising

£15,473.32



GREAT NORTH RUN

7 runners took on the world's biggest half-marathon for the TSA, raising

£10,133.43



RIDE 100

7 riders hit the hills of Surrey, raising

£10,583.04



In September 2019, we were delighted and honoured to be working with world-renowned actor Sir David Suchet CBE. **73 people** attended the fundraising event 'An Evening with David Suchet CBE' which featured the actor talking about some of his most famous roles, including his work as Hercule Poirot.

An incredible **£17,892.37** was raised from the event night itself, with a further **£3,220.51** raised by the kind generosity of Sir David in book sales and touring for his publication 'Behind the Lens: My Life'.

Tea & SCones for TSC

Our annual Tea & SCones for TSC event, where we encourage the TSC community to get baking and gather together to raise funds and awareness for TSC, did not disappoint in 2019.

There were **21 Tea & SCones** events throughout the UK, raising a brilliant

£4,655.17!



We would like to give enormous thanks to our corporate supporters:

Anglo American Foundation

Boots Community Fund

BP Foundation

Camelot Group Plc

DHL

Ensors Chatered Accountants

Hiscox

Honda of the UK Manufacturing Ltd

John Lewis Logic Park

John Lewis Leeds

Leica Cameras

Life Chiropractic Clinics

Lomax DIY

The Seafeld Ocean Club

We would like to give enormous thanks to our Trusts and Foundations supporters:

A J & K M Barnett Charitable Trust

Ardwick Trust

British Association of Dermatologists

Charles & Elsie Sykes Charitable Trust

Douglas Heath Eves Charitable Trust

Dunn Family Charitable Trust

Esher House Charitable Trust

Grace Trust

Hospital Saturday Fund

Hugh Fraser Foundation
JTH Charitable Trust

Leach Fourteenth Trust

Meikle Foundation

Michael and Anna Wix Charitable Trust

P F Charitable Trust

Rainford Trust

Rest Harrow Trust

RJM Charity Trust

Sir James Roll Charitable Trust

The 29th May 1961 Charitable Trust

The Joseph Strong Frazer Trust

The Lorimer Trust

The Tregelles Trust

Support and information

Providing support and information to the TSC community is at the forefront of the work of the TSA. 2019 was another strong year as we continued to provide a knowledgeable and listening ear on a wide range of TSC-related queries.

In 2019, we received **961** enquiries for support and information from the TSC community:

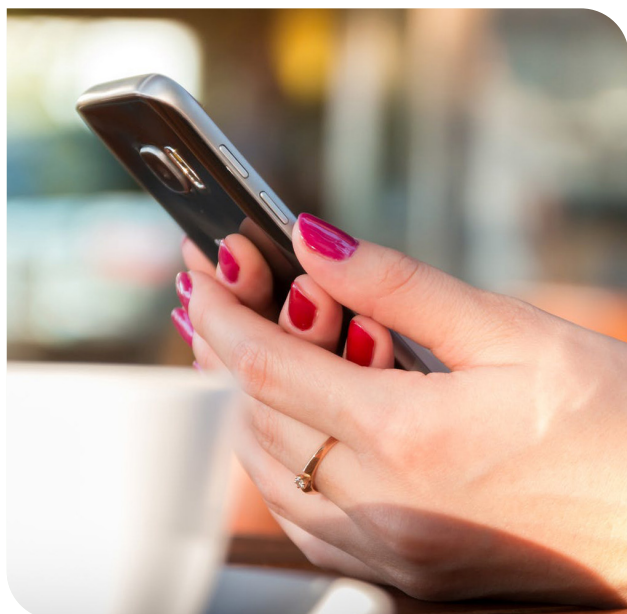
The people contacting us were most commonly:

1. Parent carers of a child living with TSC
2. Adults living with TSC
3. Parent carers of an adult living with TSC
4. TSC-focused professionals (doctors, social workers, teachers)


The most common reasons people contacted us for support were:

1. Broad health questions
2. Broad education questions
3. Referral, contact or access to TSC clinics
4. TSC diagnosis
5. The TSA Support Fund

12 enquiries led to referrals to other organisations

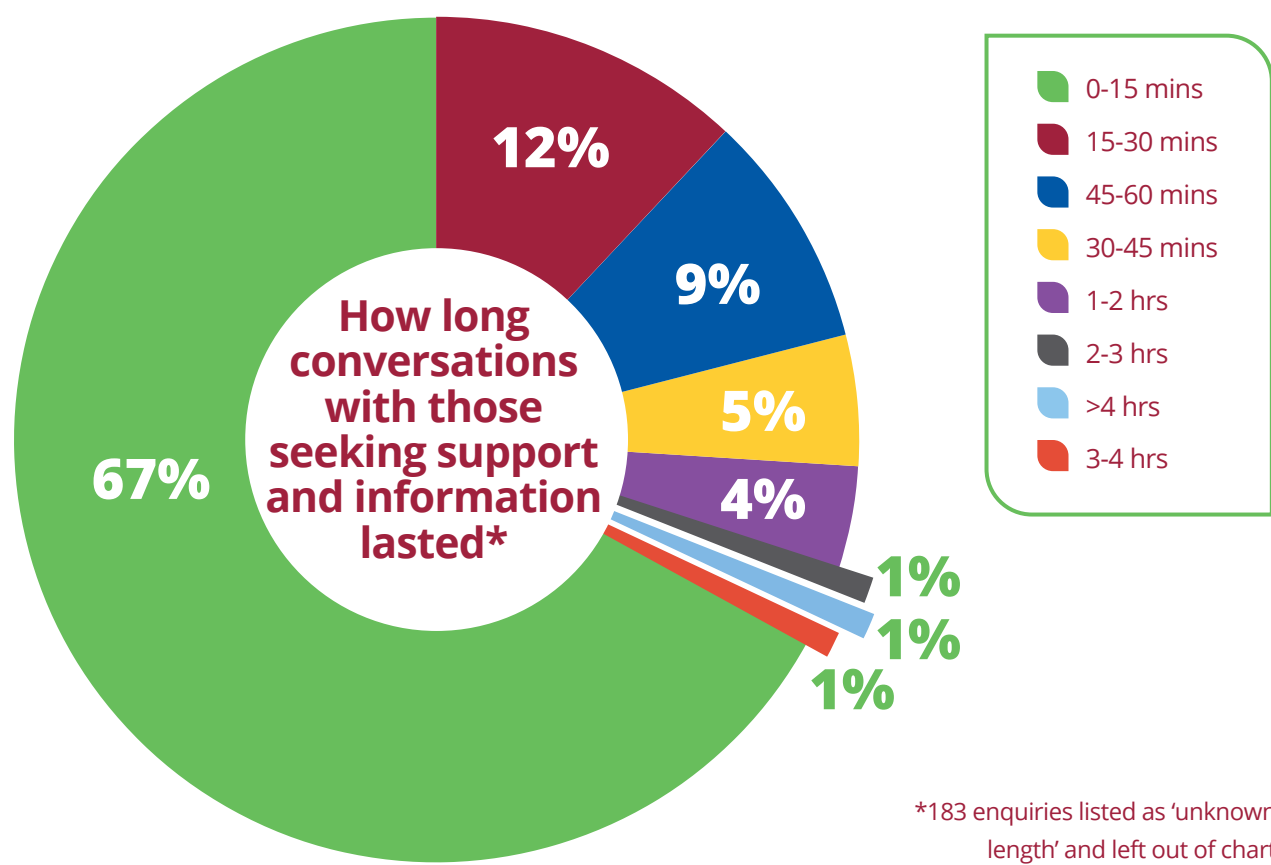
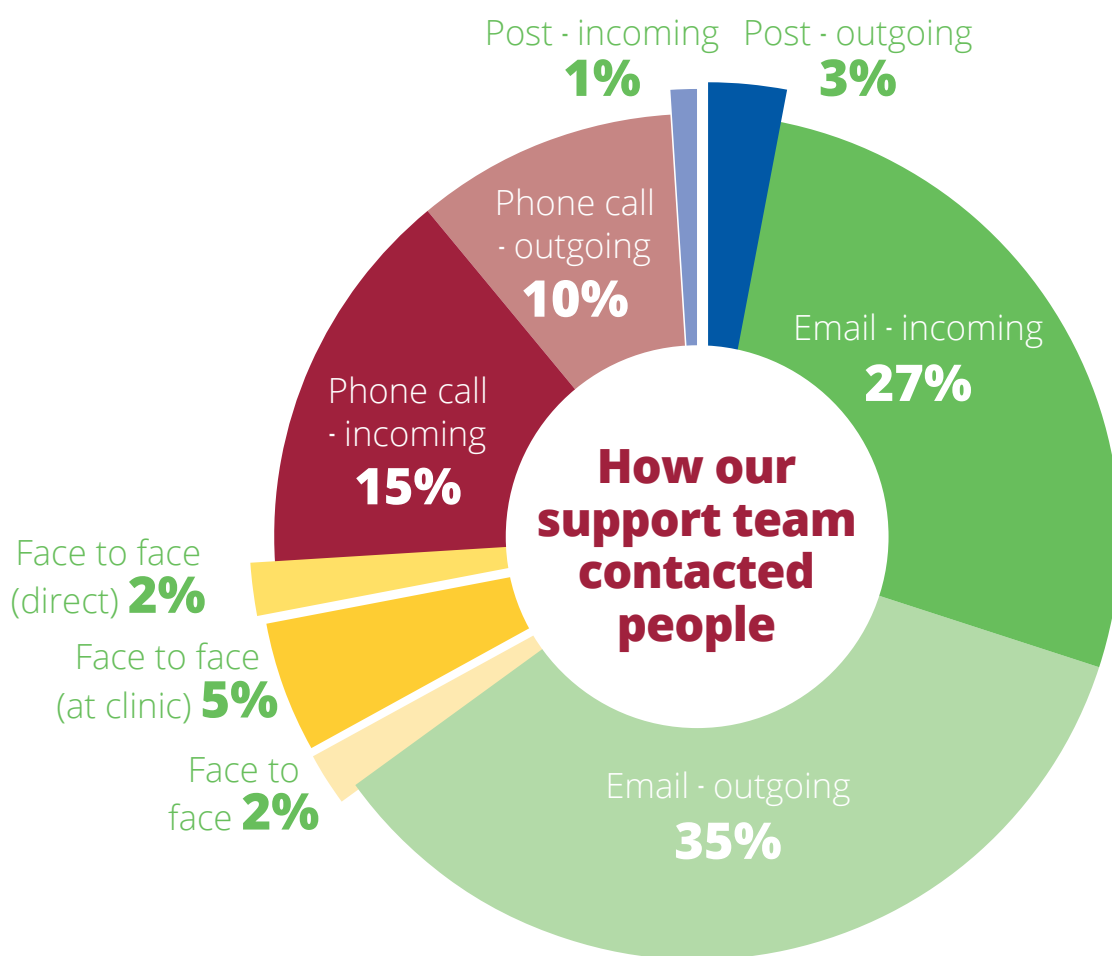


Since 2019, the TSA has launched its new TSA Support Line. Open 9am - 5pm, Monday - Friday, you can call our small team of friendly advisers to discuss any TSC topic, or to just have a listening ear:

 **0808 801 0700**

 **support@tuberous-sclerosis.org**

 **Freepost TSA**



- 0-15 mins
- 15-30 mins
- 45-60 mins
- 30-45 mins
- 1-2 hrs
- 2-3 hrs
- >4 hrs
- 3-4 hrs

*183 enquiries listed as 'unknown length' and left out of chart

The Tuberosus Sclerosis Association Treasurer's Report 2019

Strategic Report with Supplementary Information

The attached Strategic Report is reproduced in full from, and forms part of, the Report of the Trustees or the year ended 31 December 2019.

We have also attached the Summary Statement of Financial Activities (SOFA) for the year ended 31 December 2019 and the Summary Balance Sheet as at that date.

The Strategic Report (together with the SOFA and Balance Sheet) forms only part of the Association's Annual Report and Accounts. Members can obtain full copies of the Report and Accounts by emailing the Treasurer at: admin@tuberous-sclerosis.org. In addition, the full report and accounts will be available via the TSA website (www.tuberous-sclerosis.org), Companies House (<https://find-and-update.company-information.service.gov.uk>) or from the Charity Commission (www.gov.uk/government/organisations/charity-commission).

The auditors' report on the Annual Accounts was unqualified. As part of the unqualified report the auditors confirmed that the information given in the Report of the Trustees (incorporating the Strategic Report) for the financial year for which the financial statements are prepared is consistent with such financial statements.

On behalf of the Trustees

D R Vaughan, Treasurer

Tuberous Sclerosis Association

STRATEGIC REPORT FOR THE YEAR ENDED 31 DECEMBER 2019

The Tuberos Sclerosis Association (Registered number: 02900107)

Objectives and Activities

Objectives and aims, including public benefit

The Trustees confirm that they have complied with their duty, under the Charities Act 2011, to have regard to the Charity Commission's published public benefit guidelines in determining the activities undertaken by the Association.

The Association has three main objectives:

- Support individuals affected by TSC, together with their families or carers
- Encourage and support research into the causes and management of TSC
- Provide education, publicity and information to promote awareness of the problems caused by the condition

In 2019, the TSA began to implement its five-year strategy for 2019-2023 which was approved by Trustees in the previous year. The strategy sets out a clear vision (a world where TSC and its effects are conquered), continues the charity's mission (to provide help for today and a cure for tomorrow), and states that we will:

- REACH more people - significantly increasing the number of people being supported by the TSA by 2023
- Drive more REseArCH - stimulating at least the same amount of investment in TSC research during 2019-2023 as was invested by the TSA over the last five years
- Balance the TSA's finances by 2021 - having invested in research in recent years, we need to rein in expenditure and grow our income so that the charity is sustainable in the long-term

Our strategic aims (what we will do) are to:

- Make a positive impact on the health and wellbeing of people living with TSC and their families and carers
- Lead research into tools, technologies and treatments which eliminate the effects of TSC
- Lead innovation in the integration of medical and social care

Our strategic objectives (how we will do it) are to:

- Provide good quality, easily accessible and timely information about TSC and about living with the condition
- Provide the opportunity for people with TSC and their families to connect, support and learn together
- Capacity build the knowledge and expertise of professionals working with people with TSC
- Drive the research agenda with the aim of improving outcomes and quality of life for people with TSC

- Expand our understanding of the condition to accelerate diagnosis, intervention and development of new treatments
- Disseminate and use evidence to influence NHS policy and practice
- Campaign for better access to treatments and care from the NHS
- Support the development of centres of excellence for supporting people with TSC and their families
- Pilot, then roll out, innovative approaches to whole person, family and carer support

Our strategic enablers (the things that will make it possible) to deliver the strategy are:

- Effective teamwork by staff working together to achieve a shared vision
- High-quality, integrated financial management
- Digital transformation and smart working to reach more people
- An enterprising approach to income generation to drive more research

Our strategic values (the things we believe are important) are to be inclusive, ambitious and effective. 2019 was the first year of implementing the new five-year strategy. This was a year of transition for the TSA resulting in significant changes to how we work internally, what we deliver for our beneficiaries, and who we work with externally. Our 2019 Business Plan set the following priorities:

Prioritising access to good quality, accessible and timely information

- We will develop and launch a high-quality new website to reach more people with online information
- We will scope and deliver a new Support Line ready for launch in January 2020
- We will disseminate and support the implementation of new UK clinical guidelines on TSC

Providing the opportunity for people with TSC to connect, support and learn together

- We will develop and deliver a smaller number of high-quality events with more attendees at each event across England and the devolved nations

Driving the research agenda with the aim of improving outcomes and quality of life for people living with TSC

- We will develop and implement a new approach to driving investment in TSC research through joint working with partners and funders
- We will seek to fund and establish a UK TSC Registry which will pull together information from patients who have TSC
- We will continue to fund our existing research commitments during this period

Campaigning for better access to treatments and care

- We will continue to lobby for the NHS in England, Wales and Northern Ireland to fund everolimus for TSC-related epilepsy where needed
- We will identify and support existing third sector partnerships seeking to improve care for people with autism and learning disabilities. The 2019 Business Plan stated that the TSA would continue to run a deficit budget for 2019 and 2020, with a view to running a balanced budget from 2021 and on an ongoing basis from that point forward.

We were notified by our landlords in 2018 that the TSA's shared offices were scheduled for demolition the following year. We initiated a project to identify a new office space for the charity and moved to Unit 56, 1 Emma Street, London E2 9FP during May 2019.

The benefits of our activities are briefly summarised below and relate directly to our objectives. This summary constitutes our 'Strategic Report'.

Activities and performance in relation to our 'Five-year strategy'

The Trustees are monitoring performance against three headline indicators and a broader set of key performance indicators to determine the success of our new five-year strategy.

Balancing the books

The Trustees are clear that for the charity to be sustainable we need to be raising sufficient funds to ensure that the charity is making a surplus before any further research commitments are entered into, and ideally in the longer term raising sufficient funds to cover the research commitments. During 2019 the Trustees took a number of steps to address the structural and recurring loss that is accelerating the reduction in the Designated Endowment Fund of the charity. In the first year of our new strategy we initiated operational changes that will generate savings or increase income in future years, including reducing planned headcount from 21 to 13 posts, reviewing our expenditure, refreshing our approach to income generation to broaden the ways that we raise money to fund our work, and approving a new research partnership strategy.

Reaching more people

In 2018 the TSA had 1,600 people living with TSC and family members on our database. We believe there are somewhere between 3,700 and 11,000 people living with TSC in the UK and we aim to significantly increase the number of people being supported by the TSA by 2023. In the first year of our new strategy we increased the number of people on our database by 15 per cent (793 new contacts) and increased the number of people following the TSA on Facebook by 17 per cent (572 new followers).

Driving more research

During the past five years (2014-2018) the TSA has invested **£1,775,000** in research. We aim to drive the same amount of investment into TSC research during 2019-2023 as we invested directly over the last five years. In the first year of our new strategy the TSA invested **£152,000** which unlocked **£728,000** of co-funding from external partners including the King Baudouin Foundation, the US Ministry of Defence and an anonymous major donor, driving a total new investment of **£890,000** in TSC research.

Activities and Performance in relation to 'Support'

Our commitment is to offer support to everyone affected by TSC based on individual needs and preferences. We aim to address diversity, including geographical and cultural diversity of need. Key to our success is making the support we offer as flexible as possible, enabling individuals, families and carers access to the support and information they need in the way that suits them best.

During 2019 we responded to 961 enquiries from members of the TSC community who contacted the TSA asking for information and support. 19% of enquiries came from adults living with TSC, 16% from parent carers of adults living with TSC, 29% from parent carers

of children living with TSC, and 11% from professionals supporting individuals and families living with TSC.

In 2019 the Trustees made the difficult decision to move from a regional support service to a Support Line which could be delivered by a smaller number of staff. The support services team was restructured from nine posts to four, and sadly we said goodbye to seven hardworking and valued members of staff whose regionally focused posts were made redundant. Their loss was keenly felt by trustees, staff and the wider TSC community.

During Autumn 2019 we began the transition to the new Support Line which launched as a pilot in early 2020. The Support Line enables the TSC community across the UK to contact our small team of friendly and professional advisers confidentially by telephone, email and post from 9am to 5pm on Monday to Friday each week. The TSA joined the Helplines Partnership to access high quality advice and training and ensure that the development of our new service is informed by best practice across the health and social care charity sector.

We continue to build our relationship with NHS TSC clinics through our annual TSC Clinics Day which brings together clinic leads (usually senior clinicians) and clinic coordinators (usually nurses) from the 15 clinics in England and one clinic each in Scotland, Wales and Northern Ireland. Regular contact with the staff leading and managing the clinics helps to facilitate:

- Working in partnership with the clinics, supporting patients and their families
- Providing support and information to the clinics in relation to education, social care and welfare
- Signposting patients with wider support needs to external agencies across social care, education and welfare
- Signposting to and facilitating engagement with the portfolio of TSA services

During 2019 we awarded £5,700 in grants from the TSA Support Fund to individuals and families.

Activities and performance in relation to 'Influencing policy'

NHS England funded everolimus for TSC-related epilepsy from April 2019 onwards as a result of intense campaigning from people living with TSC, their families and the TSA, to reverse their earlier decision due to the clear clinical evidence shown to commission the medicine. During 2019 we continued to support members of the TSC community in Wales and Northern Ireland who wished to access everolimus for TSC-related epilepsy. We also met with NHS England to focus on finding solutions for the practical challenges faced by NHS trusts when implementing the recommendations to fund everolimus for TSC-related epilepsy.

We supported the implementation of new UK clinical guidelines on TSC, which are an evidence-based tool aiming to improve the consistency and quality of care across the NHS. We worked with the UK experts who developed the guideline to produce a summary version for clinicians which was disseminated to NHS clinics and professionals across the UK, and distributed the summary version to patients and carers with our Spring Scan magazine to facilitate informed conversations with the professionals caring for them. We also published an easy read version of the summary clinical guideline to help

individuals with learning disabilities and their family carers to discuss and understand the recommendations. We have formed successful alliances with other charities and worked with them on a range of activities and initiatives with the common aim to raise the profile and importance of rare disease with Parliamentarians and Policy Makers. During 2019 we continued to work closely with colleagues from the Specialised Healthcare Commissioning Alliance (SHCA) and Genetic Alliance to raise awareness of the need for NHS England and NICE to listen to the views of patients and families when making decisions about treatments and services for people living with rare diseases. We joined the Embracing Complexity Coalition to raise awareness of the need for joined up support from health and social care for people with complex conditions, and continued our membership of the Council for Disabled Children to improve access to services and care for children living with TSC and their families.

Activities and performance in relation to 'Information & awareness'

We worked hard to make all of our information and resources available on a new website (www.tuberous-sclerosis.org) for individuals with TSC, their families and the professionals who support them. The website also showcases our new five-year strategy to external charity funders and partners, demonstrates our research credentials to potential research funders and partners, and makes it easier for people to donate money to us or raise funds for the charity. The website was funded by **£13,000** of grants from trusts and foundations to develop a website with a simple back-end system that can be updated in-house to make savings year on year. We also produced and published three editions of our Scan magazine to ensure continued access for members of our community who may be less comfortable with online communications.

Raising awareness of the TSA and our services has been key to reaching new families. The more professionals, opinion leaders, politicians, policy makers and the media know about TSC, the more likely we are to bring about positive change. During 2019 there were 10 articles about TSC in the regional and local media, and 7 articles across the medical and third sector press.

During 2019 we received an amazing boost to our awareness-raising from award-winning actor Sir David Suchet CBE who hosted a black-tie fundraising dinner for 70 guests which raised **£17,982** for the charity. Sir David used the launch of his new book 'Behind the Lens' to raise awareness of TSC and the TSA across print and broadcast media, generating coverage in Hello magazine, seven national newspapers, ITV's This Morning, BBC Radio 4 and BBC Radio 2. Sir David raised a further **£3,220** for the charity during his book launch and tour events and decided to donate any profits that his book makes in future to the TSA for us to invest in TSC research. We would like to thank Sir David and his wife Sheila for their incredible generosity and kindness to the charity and the individuals and families who we support.

In May 2019 we ran our awareness and fundraising campaign 'Tea and SCones for TSC' which raised **£4,655** and coincided with TSC Global Awareness Day. Our fantastic runners and riders raised funds for the TSA at the London Marathon (**£15,473**), Great North Run (**£10,133**) and Ride100 (**£10,583**) In line with our new strategy, we delivered a smaller number of high-quality events across England (the Big Day, Outlook and a Family Fun Day), Scotland (Scottish Get Together), Wales (Welsh Information Day) and Northern Ireland (Northern Ireland Study Day). Our aim was to increase the number of people attending

each event to facilitate networking between individuals and families with lived experience of TSC who are able to support one another, and 274 people registered to attend at least one of our events in 2019.

Activities and performance in relation to 'Research'

The Association is the only UK charity dedicated to supporting TSC research, with an in-year Research Grant commitment in 2019 of **£265,618**, as shown in note nine to the financial statements.

In 2019, of the nine awards that submitted data, four awards reported six publications in four different academic journals. Five awards reported 13 other forms of engagement, such as oral and poster presentations at academic conferences or professional meetings.

During the year the Trustees approved a new research partnership strategy based on working with external partners who share our goals and can co-fund TSC research projects. During 2019 we invested in three new research projects where the TSA will inject a total of **£152,000** to unlock **£728,000** of co-funding from external partners, driving a total new investment of **£890,000** in TSC research.

Co-funded Projects

Investigator	Institution	Title	Co-funder
Dr Elaine Dunlop	Cardiff University	A model of cell invasion in TSC-LAM	US Ministry of Defence
Professor Petrus de Vries and Professor Anna Janssen	University of Cape Town and University of Brussels	The TANDem Project	King Baudouin Foundation
Dr Sam Amin and Dr Ingram Wright	University of Bristol	Better understanding the accessibility of mental health services for children and young people with TSC	Anonymous major donor

In addition, we agreed to fund the Early Development in Tuberous Sclerosis (EDiTS) study being carried out by the Institute of Psychiatry, Psychology and Neuroscience with a commitment of **£16,740** and renewed three projects - two with Cardiff University and one with the Whitehead Institute - with commitments of **£116,074**.

Full details of the commitments reached during 2019 are shown in note nine and 19 to the financial statements. This takes our full portfolio in 2019 to 12 live grants, three of which are jointly funded. Our portfolio of ongoing projects is worth **£1,227,575**.

We continue our membership of Association of Medical Research Charities and the UK Child Health Collaboration.

Activities and performance in relation to 'Investment policy'

The Trustees have appointed investment managers to manage the Association's investment portfolio under a discretionary investment mandate. Our investment objective is to maximise total returns over the longer term and to provide a stable level of income to be generated with a medium level of risk. The level of risk applies to the portfolio as a whole rather than to individual stocks. To measure the performance of the investment portfolio the Association has, in common with other charities, adopted the ARC Steady Growth Charity benchmark. In the year ended 31 December 2019, the total return on the portfolio was 16.16% as against the benchmark of 15.65%. Over the longer term, our investment managers have consistently out-performed the benchmark. Their performance continues to be kept under review and those Trustees who are members of FINCOM have an annual review meeting with them. The Trustees have agreed a formal investment policy reflecting the investment objective stated above.

Activities and performance in relation to 'Volunteering'

The Association benefits from the contribution given by volunteers and would like to take this opportunity of thanking all volunteers who have helped it work towards meeting its objectives.

FINANCIAL REVIEW

Grant making policy

Research grants are given for purposes directly concerned with furthering an understanding of Tuberosus Sclerosis Complex and its treatment. The Association is a member of the Association of Medical Research Charities and follows AMRC policy in the conditions attached to awarding grants. All applications are peer reviewed.

Benevolent grants are given to families to purchase necessary medical or household equipment, or to provide parents, carers and families with much-needed breaks. All applications for assistance are reviewed by the Chief Executive or the Head of Support and Information Services and grants awarded where deemed appropriate on a basis of confidentiality, based on the Association's guidelines. Trustees are eligible to apply for such grants and are dealt with in the same way as any other applicant.

Statement on reserves & review of financial position

At the end of the year the Association has total funds of **£1,218,696**. This included Restricted funds of **£4,700**, not available for the general purposes of the Association and designated funds of **£1,023,996**, further details of which are given below. It is anticipated that the designated funds will be fully spent by 31 December 2022.

The reserves of the Association at 31 December amounted to **£190,000** at 31 December 2019, representing three months of expenditure excluding any research commitments entered into. A transfer of **£686,057** has been made from the Designated Endowment Fund to provide these reserves.

Designated Fund

The funds of the Association includes a designated fund which largely arises from a bequest in 1993 by the late Mr H I Leech. This does not form part of the Association's reserves.

This fund has been broadly treated as an "endowment" and invested with professional advisers to provide a resource which supports the Association in delivering its charitable objectives. In particular, it enables the Trustees to:

- Fund or co-fund out of capital (and, if need be, at short notice) major medical research projects which are determined by the Trustees to be crucial for the treatment of TSC
- Help fund the charitable activities from investment income, thereby helping to secure the future of the charity and provide continuing support to future and current sufferers of TSC

In recent years, the balance on the Designated Fund has reduced significantly as a result of both additional research commitments and the provision of additional services, the cost of which have not been covered by the income of the Association.

The commitments that the Association intends to make in the forthcoming years (including Research that has already commenced and is renewed on an annual basis, subject to a satisfactory review) are such that the trustees expect the Designated Fund to reduce to approximately **£300,000** by 31 December 2022. The trustees are of the opinion that this minimum designated fund balance should be retained so that the Association has sufficient funds to instigate major medical research projects, co-funded by third parties, at short notice if necessary.

Result for the year

The Association's total income for the year was **£303,000** (2018 **£324,000**).

Our total investment gains/ (losses) were **£208,000** (2018 - **£219,000**). To fund deficits and payments relating to research commitments entered into during the year, some investments needed to be sold to provide the Association with additional working capital. Taking into account the investment gain, the overall deficit for the year was **£489,000** (2018 - **£871,000**).

Risk Management

The Trustees have established procedures to ensure that strategic planning and risk management processes become part of the operating processes of the Association. The Trustees have identified the major risks to which the Association is exposed, determined the relative significance of those risks, and reviewed the adequacy of the systems that have been established to mitigate those risks. Further details are given in the section headed 'Structure, Governance and Management' of the Report of the Trustees.

FUTURE PLANS

2020 Business Plan

The 2020 Business Plan was approved in November 2019. In the second year of implementing the new five-year strategy 2019-2020, we planned to reach more people and drive more research by prioritising delivery of the following strategic objectives:

Providing access to good quality, accessible and timely information

- Launch new free and confidential Support Line in January 2020 and make sure it meets people's needs for emotional and practical support
- Continue to build high-quality new website and social media channels to reach more people with online information

Providing the opportunity for people with TSC to connect, support and learn together

- Refresh Ambassadors role to welcome those with a new diagnosis to the TSA
- Introduce more regular Family Fun Days so that people living with TSC and their families can get together informally to talk and network
- Hold a TSC Community Education Afternoon so that people living with TSC and their families see the latest research from international experts on TSC

Capacity building the knowledge and expertise of professionals working with people with TSC

- Develop a new approach to working with NHS TSC clinics and publish online resources to help those living with TSC to prepare for clinic visits
- Introduce a training programme for health, social care and education professionals to help them provide the best possible care when working with people living with TSC and their families

Driving the research agenda with the aim of improving outcomes and quality of life for people living with TSC

- Implement new approach to driving investment in TSC research through joint working with partners and funders rather than using the TSA's Designated Endowment Fund
- Host the 2020 International TSC Research Conference in London

Campaigning for better access to treatments and care

- Contribute views of people living with TSC and their families to NICE and SMC decision-making on Epidiolex® (cannabidiol) for TSC-related epilepsy
- Support NHS England Clinical Reference Group review of TSC service delivery
- During 2020 we planned to continue reducing expenditure and increasing income with an ambitious goal of balancing the TSA's budget by 2021

Revisions to 2020 Business Plan as a result of Covid-19

The Trustees carried out an urgent review of the 2020 Business Plan in April 2020 as a result of unprecedented changes in the external environment due to the coronavirus pandemic. We paused delivery of our planned strategic objectives, and agreed a revised 2020 Business Plan with a focus on the following priorities:

Supporting people living with TSC and their families during this difficult time by:

- Sharing high quality, timely and accurate information about coronavirus and TSC developed by the TSA on our website, newsletter emails and social media channels
- Proactively sharing high quality, timely online content developed by larger charities when it will be relevant and helpful for the community
- Providing emotional support and tailored information for individuals and families who need help primarily through the new Support Line and those that contact us via social media and other means
- Developing regular and innovative ways for the TSC community to keep in touch with one-another through digital channels, including bringing people together virtually (for example for virtual Tea and SCones or virtual Outlook) to reassure them that they are not alone while socially-isolating or self-shielding
- Developing regular and innovative ways for the TSA and TSC community to keep in touch through the post with individuals and families who are not active online while they are socially-isolating or self-shielding

Ensuring the survival of the charity by:

- Furloughing six members of staff to maximise income and safeguard future employment, and asking senior staff to work reduced hours to generate further savings
- Reviewing the 2020 non-pay budget to make savings against the strategic objectives that have been paused
- Sending out a 'direct mail' fundraising ask for regular direct debit support or one-off donations during a period when people can clearly see the value that we are adding
- Sharing consistent fundraising asks to the TSC community via digital channels about indoor

activities that can still take place during the pandemic

- Rebuilding our trusts and foundations fundraising, since the funding given is less likely to be affected even if the mechanisms for decision-making may cause some delays during this period

We have moved the 2020 International Research Conference from November 2020 to July 2021 to minimise the likely impact of the pandemic on delegate numbers, delegate income and sponsorship.

In June 2020, in light of significantly reduced income as a result of Covid-19, the Trustees made the difficult decision to make staffing cuts of 30% and to continue to ask remaining staff to work reduced hours to enable us to run sustainably at a projected much-reduced income level until 2022. The Designated Endowment Fund will be used to fund the already sunk costs of hosting the International Research Conference which has been postponed to 2021 and to cover the cost of our ongoing research grants programme in 2020/2021. The Trustees' goal is to retain our reserves at a sensible level so that we give ourselves the best possible start in 2022 to grow the charity and deliver the ambitions set out in the five-year strategy 2019-2023. Further details are given in the Financial Review.

The TSA's Trustees and staff remain ambitious about what we want to achieve for the TSC community. We're determined to ensure that Coronavirus won't stop us being here for individuals living with TSC and their families, and our mission remains unchanged: to provide help for today and a cure for tomorrow.

The Tuberosus Sclerosis Association

Summary Statement of Financial Activities

For year ended 31 December 2019

	Year ended 31/12/19 £	Year ended 21/12/18 £
INCOME AND ENDOWMENTS		
Donations and legacies	£234,374	£208,515
Charitable activities		
Family care & support	1,510	2,690
Education	-	19,849
Other income		
Other trading activities	1,756	8,235
Investment income	65,176	84,532
Total	302,816	323,821
EXPENDITURE		
Raising funds	157,232	153,301
Charitable activities:		
Family care & support	260,465	287,111
Research	385,572	386,875
Promoting awareness	133,138	92,916
Education	64,054	54,443
Total	1,000,461	974,646
Net gains/(losses) on investments	208,190	(219,967)
NET INCOME/(EXPENDITURE)	(489,455)	(870,792)
RECONCILIATION OF FUNDS		
Total funds brought forward	1,708,151	2,578,943
TOTAL FUNDS CARRIED FORWARD	1,218,696	1,708,151

The Tuberosus Sclerosis Association

Summary Balance Sheet

For year ended 31 December 2019

	2019	2018
	£	£
FIXED ASSETS		
Tangible assets	851	-
Investments	1,268,946	1,914,135
Total	1,269,797	1,914,135
CURRENT ASSETS		
Debtors	98,608	21,292
Cash at bank and in hand	264,938	196,226
Total	363,546	217,518
CREDITORS		
Amounts falling due within one year	(414,647)	(423,502)
NET CURRENT ASSETS	(51,101)	(205,984)
TOTAL ASSETS LESS CURRENT LIABILITIES	1,218,696	1,708,151
NET ASSETS	1,218,696	1,708,151
FUNDS		
Unrestricted funds:		
General fund	190,000	-
Designated Endowment Fund	1,023,996	1,473,818
Kilmaine Family Research Fellowship	-	228,912
Total	1,213,996	1,702,730
Restricted funds:		
Research	4,700	-
Education	-	5,421
TOTAL FUNDS	1,218,696	1,708,151

We would like to give thanks to our Trustees for all of their work:

Sanjay Sethi – Chair

Martin Short – Deputy Chair

David Vaughan – Treasurer

Thomas Carter

Chris Kingswood

Lisa Suchet

Patrick Bolton

Philip Goldenberg (resigned June 2019)

Robert Woodthorpe Browne

Frances Elmslie (appointed June 2019)

Jane Rogers (appointed June 2019)

Annemarie Cotton (appointed June 2019)